DOCUMENT RESUME

ED 442 222 EC 307 858

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TITLE Focus on Vermont's Self-Determination Project.
SPONS AGENCY Syracuse Univ., NY. Center on Human Policy.; National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.; Minnesota Univ., Minneapolis. Inst. on Community Integration.
PUB DATE 1998-00-00
NOTE 15p.
CONTRACT H133B980047
PUB TYPE Reports - Descriptive (141)
EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Adults; Case Studies; Change Strategies; Children; Delivery Systems; *Developmental Disabilities; Focus Groups; Models; *Personal Autonomy; Program Evaluation; Self Advocacy; *Self Determination; *Systems Approach; Teamwork; Training
IDENTIFIERS *Vermont

ABSTRACT

This paper reports on a focus group discussion held in June, 1998, in Killington, Vermont, about a 3-year project in Vermont to encourage the self-determination of people with developmental disabilities. The project has involved training of four project teams, each composed of a person with a developmental disability, a family member, and a person experienced in providing services. The responses of the 60 focus group participants are summarized in a model of self-determination involving different aspects of the individual, sources of support, and life processes and a selection of their comments concerning their understanding of self-determination, what support includes, and examples of self-determination. Also reported are system challenges identified by the group such as accounting for the system's money in a way that is clear to people and their families and potential pitfalls such as exclusion of people based on unwarranted assumptions. Finally, the most important contributions of the self-determination project are identified including strengthening of self-advocacy organizations, realization by agency managers of new ways to foster self-determination, and a reconsideration of many aspects of case management. (DB)

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ED 442 222

FOCUS ON VERMONT'S SELF-DETERMINATION PROJECT

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This paper was supported through a subcontract from the Center on Human Policy, Syracuse University for the Research and Training Center on Community Living. The Research and Training Center on Community Living is supported through Cooperative Agreement No. H133B980047 between the National Institute on Disability and Rehabilitation Research (NIDRR), Office of Special Education and Rehabilitative Services, U. S. Department of Education, and the University of Minnesota, Institute on Community Integration. Members of the Center are encouraged to express their opinions; these do not necessarily reflect the official position of NIDRR.

EC 307858

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Focus on Vermont's Self-Determination Project

This report summarizes a focus group discussion held on 22 June 1998 in Killington, VT as part of The Center on Human Policy's support to the learning community for Vermont's Robert Wood Johnson funded self-determination project. About 60 people participated in the focus group, which met from 9:30 AM to 3:00 PM. The majority of participants were people involved with the Vermont Peer Support Network and family members and members of the self-determination project staff. DDS staff and UAP and DD Council staff involved with the project advisory group were represented. While a number of people who work as case managers or support staff attended, the perspective of people with administrative responsibility for designated agencies and other provider agencies was largely missing from the focus group. John O'Brien facilitated the group and prepared this record based on large charts prepared during the meeting and checked with participants for accuracy.

The large size of the group may have made participation difficult for some people, as did the fact that some people attended the focus group as their initial orientation to the self determination project. A few more than half of the participants spoke or contributed through vivid gestures. Because the goal of the meeting was to collect as many different points of view on the self-determination project as possible, there was no expectation that the group would reach consensus and not everyone who attended would agree with all of the points in this summary.

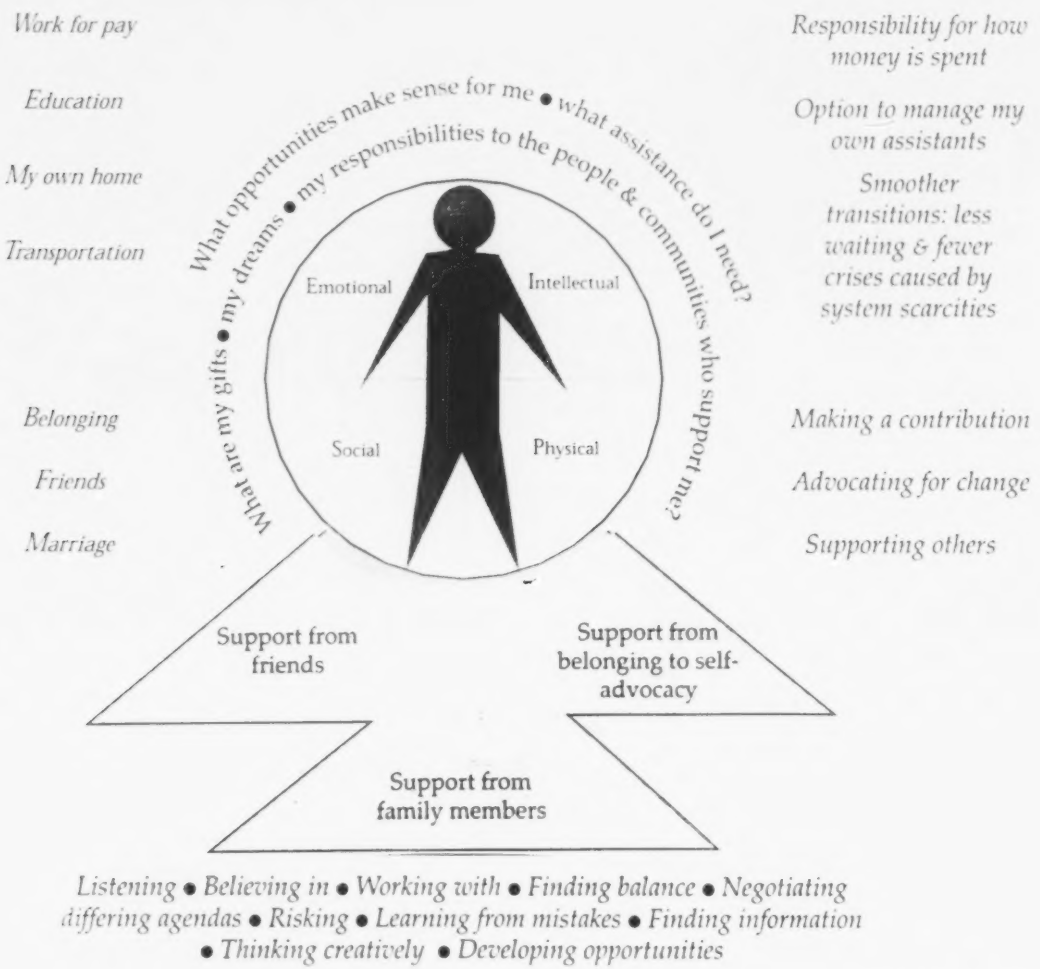
This focus group met about ten months after the project director began work and about two years from the end of the Robert Wood Johnson funded project. The four project teams have completed their initial training and have begun work with about 40 people. Referrals to the teams are expected to grow in the coming months as more people and their families hear of the project. Given this timing, and the composition of the group, the focus group discussed the current state of the service system and ideas about what the self-determination project will become more than what the project has achieved so far.

It is important to note that the development of the four project teams itself constitutes an important achievement. Each team of three includes a person with a developmental disability, a family member, and a person experienced in providing services. The project staff have learned important lessons about sharing responsibility for the team's tasks and working out mutual accommodations so

that differences in skills and experience create strengths for the team. As one focus group member noted, the teams themselves constitute a model for working and learning collaboratively.

Moreover, the project embodies commitment among leaders within and outside DDS to manage the Division's mandated restructuring in a way that promotes positive changes. Their goal is for the restructured system to offer people with developmental disabilities and their families as much say as possible in the way services are planned and provided within the limits of available, flexibly managed public money. The principles articulated in designing the self-determination project have strongly influenced the regulatory and policy changes necessary to implement the Department's Restructuring Plan.

An understanding of self-determination


Work for pay
Education
My own home
Transportation
Belonging
Friends
Marriage
Responsibility for how money is spent
Option to manage my own assistants
Smoother transitions: less waiting & fewer crises caused by system scarcities
Making a contribution
Advocating for change
Supporting others
What opportunities make sense for me • what assistance do I need? • my responsibilities to the people & communities who support me? • my dreams • What are my gifts
Emotional
Intellectual
Social
Physical
Support from friends
Support from belonging to self-advocacy
Support from family members
Listening • Believing in • Working with • Finding balance • Negotiating differing agendas • Risking • Learning from mistakes • Finding information • Thinking creatively • Developing opportunities

This diagram summarizes participants' current understanding of self-determination as the living process that the project exists to support.

People with developmental disabilities will have a meaningful say in the way publicly funded services support them to live their lives when...

...they have a greatly increased responsibility for deciding on the way public funds are expended to assist them (people will rely on the help of friends, family members, or sometimes guardians, as well as the advice of knowledgeable service providers to discharge this responsibility sensibly)

... they have the option to manage the hiring, firing, training and supervision of their own assistants, usually with help from the people who support them

...they see themselves and are seen by others as whole people with gifts, dreams, and responsibilities which matter to the people and communities to which they belong

...they see themselves and are seen by others as developing people whose time of life, life experiences, and disabilities call for self-knowledge and thoughtful, well informed recognition of the sorts of assistance they need (One of the participants finds the fourfold way depicted in the diagram of understanding herself as a whole person developing socially, physically, emotionally, and intellectually particularly helpful in figuring out the sorts of assistance.)

...they have the support of people close to them, including family members, friends (including friends among those paid to do human service work), and members of disability advocacy groups: this support includes

- listening in a way that encourages self-understanding and positive expectations
- believing in the person's worth and their capacity and responsibility to contribute to others
- finding relevant information about how others have accomplished important goals such as finding a good job, pursuing educational interests, having one's own home, or advocating effectively on issues of importance
- thinking creatively with the person in a way that challenges the person and important others to figure out how to make what matters most to them happen
- helping people (including people with disabilities and their family members and other supporters) to seek a balance between their individual desires and their effects on other people who matter to them

Support includes...

- recognizing that agendas differ, even among people who care deeply for each other, and finding ways to deal with important differences in fair and creative ways
- encouraging –or not discouraging– risks that are important to the person's development and enjoyment of life
- helping the person to bounce back and learn from mistakes and misfortunes
- working with the person to develop new and personally meaningful opportunities, especially when doors to important experiences are blocked by prejudice or unexamined habits of inaccessibility or untested inflexibility in human service practice
- helping the person develop relevant skills and discover accommodations that extend competency

People have a meaningful say when...

...professionals and service managers recognize that a need for assistance doesn't take away a person's or a family's knowledge of what really matters and what helps; indeed, it provides an essential perspective for setting the direction of and judging the effectiveness of professional and managerial work

...they can count on designated agencies and service providing agencies to push the limits of the system to maximize the flexibility of the assistance that they offer

...they can count on designated agencies and service providing agencies to invest systematically in efforts to increase local opportunities for paid work, relevant education, support for people living in their own homes (including help with home ownership), convenient and affordable transportation, and more open and hospitable local places and associations

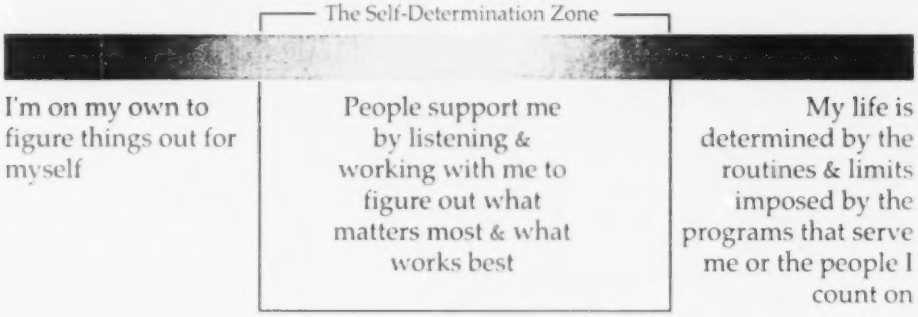
...service resources and usual practices are sufficient to allow smooth and planned transitions when a person's life changes: people can get the assistance they need to move on from their parental home to set up their own households without waiting for a crisis that threatens homelessness; people who want to move from a developmental home into a place of their own have access to the assistance they need to do so; planning for graduation from school leads to continuing support rather than a wait; people who want to can make job changes without losing their current job

Agencies that want to play a constructive role in assisting people and those committed to support them to experience genuine empowerment will often have to learn to do new things in new ways. The developmental disabilities

system will need to learn new and even more flexible ways to stretch existing resources (and probably to attract support for sufficient additional funding) to make transitions easier, waiting periods more reasonable, and eligibility requirements more rational. The system will never be in a position to make all of people's wishes come true, but giving people access to a reasonable individual budget is likely to stimulate new approaches.

Developing the capacity for self-determination is a life long process. No one should be excluded from the kinds of support described here because of age, current ability to communicate, apparent severity of disability, or legal status. People with developmental disabilities who are involved with the criminal justice system pose a particular challenge to self-determination: for them the issue may be how to make the most of legally restricted freedom.

Understanding self-determination in this way makes it possible to define a sort of "self-determination zone". People who lack active support for self-determination, either because they are enmeshed in a set of routines designed to efficiently manage disability and minimize uncertainty for care providers or because they are abandoned to make it in isolation are outside the zone.


The Self-Determination Zone
I'm on my own to figure things out for myself
People support me by listening & working with me to figure out what matters most & what works best
My life is determined by the routines & limits imposed by the programs that serve me or the people I count on

The self-determination zone can be a place of emptiness, especially when a person has (almost) no one with a lasting personal commitment to make life better. The self-determination zone can be a place of uncertainty, especially when a person's communication is very difficult to understand or a person or a family has low expectations based on very limited experiences of what is possible. The self-determination zone can be a place of sorrow, especially when a person suffers pain or misfortune for which there seems to be no adequate reason or relief. The self-determination zone can be a place of conflict, especially when those who support a person disagree strongly about what is possible and desirable for a person or when a person does things that frighten, offend, or hurt supporters. But whatever the state of relationships, whether

confused or sad or conflicted, the self-determination zone is a place of people struggling to make and maintain good and caring relationships.

Note that people who rely on guardians or people who value the opinion of a parent above any interest in taking steps on their own can be in the self-determination zone as long at the guardian or parent is willing to join in the activities of support described above. Guardians who listen to their wards, believe in the gifts of their wards, encourages their wards in new experiences, and actively seek information and collaborate in exploring new possibilities are better able to fulfill their responsibilities than guardians who protect themselves by "just saying no."

Important questions & system challenges

The developmental services system is restructuring to apply the principles of managed care. This means more local authority for resource allocation decisions; incentives for effective money management; a clearer distinction between designated agencies, whose function is planning/purchasing service in a region, and certified providers, whose function is offering services; and a greatly strengthened emphasis on guiding the system by assessing outcomes for individuals. By assisting interested people with developmental disabilities and their families to pursue positive changes in their lives, the self-determination project keeps important questions on the restructuring agenda. The challenges involved in answering these questions include…

- Accounting for the system's money works in a way that is clear to people and their families and creates real and accessible opportunities for people and their families to make personal decisions about how to best use available money and what trade-offs to make in the face of scarcity in their individual budget.
- Demonstrating the value people and their families get from expenditures on designated agency functions so that people don't feel cheated of their share of the available funds.
- Maintaining sufficient reserves to allow for changes in people's needs without excessively constraining what people can do and clarifying the risks and responsibilities that people assume when they take control of their own budgets.
- Dealing openly and in a spirit of creative negotiation with people whose requests are turned down. As one participant put it, "A person has been told that a move from a developmental home to supported apartment living

isn't possible, but the person and their team can't find out the reasoning behind the decision. It's like a closed case."

- Discovering the conditions under which more satisfying services can be delivered more cheaply. Some assumptions that can be tested through work on self-determination in the context of system restructuring include...
  - ...there are unused financial resources available to people outside the DDS system
  - ... people who have grown up with their families and attended special education will require substantially less assistance than people who were institutionalized to pursue lives of satisfying quality
  - ...given a choice, a sufficient number of people will ask for fewer or less costly services
  - ...given the ability to direct expenditures, other people will assume responsibility for some tasks the system now pays for (this will result in greater satisfaction but not necessarily less cost if the money that is freed is directed to other purposes, such as raising salaries for assistants)
  - ...there are significant savings available from decreasing regulation in favor of increased emphasis on measuring outcomes
  - ...there are significant savings available from "cutting out (cutting down) the middle-men" in the system
- Mobilizing untapped potential for natural supports that will not only enhance quality but reduce costs, especially given that many families are already making considerable use of help from family and extended family members and that many agencies are dealing with scarcity by searching for more volunteer labor in communities where more and more people need to work for pay.
- Dealing creatively with the consequences of accumulating individual choices. For example, if a sufficient number of people choose to spend their case management funds outside an agency that now provides case management, the case management program may lose its fiscal viability while still satisfying some people.
- Learning to make good use of the consultation, training and technical assistance available through the self-determination project teams without trying to turn responsibility for coordination or service provision over to the project team.

- Avoiding the temptation to make self-determination a kind of dumping ground for people who are difficult to serve or families whose demands are difficult to meet.

Given that the system is in a period of anxiety around the shift of responsibility for money allocation decisions from DDS to designated agencies, it is easy to understand that some agency managers and staff might try to convert the uncertainties of these challenges into a sort of myth that pretends a settled conclusion to what is, in reality an open question. Such myths include...

- "All self-determination related proposals have to be cheaper than existing arrangements."
- "The self-determination project is primarily for people and families who are very dissatisfied with the services they get now."
- "If you participate in the self-determination project, you have to hire and supervise your own staff and assume all of the liabilities of being an employer."
- "The medicaid waiver's categories do not allow flexible use of funds."
- "People who participate in self-determination have to get a large proportion of the assistance they need from volunteers."
- "The self-determination project teams take over responsibility for services to people who participate in the self-determination project."
- "People who participate in the self-determination project are in competition with people who are satisfied with existing services: they will destroy existing programs by taking money out of them."

Each of these myths reflects and amplifies the fear of major changes. Broadcasting good information will limit the damage of some of these myths, but only a willingness to get involved in learning different ways to deal with people, families, community members, and systems will get to the root of the myths.

A growing number of people can make an important contribution to this learning process. They are agency staff who play a role as helpers in self-advocacy groups. Their dual role allows them to see the agency they work for in new ways. Managers and staff often assume that the people their agency assists has the same understanding of things that they do. This can lead them to assume agreement or common understanding when people have a very different understanding. Those staff who bridge the two worlds can help people on each side notice when they don't know there is a difference in understanding.

Potential pitfalls

At least four pitfalls threaten to trap the self determination project and limit its effectiveness:

- People will be excluded by assumptions that self-determination is only for people of a certain age, level of ability, capacity to communicate with and direct others, or legal status. Falling into this trap would exclude all but able adults who have their own guardianship and can independently direct their own assistants.
- People will be denied opportunities to develop their voices by gathering new information, discovering a new understanding of their rights, and exploring new possibilities: "She says she's highly satisfied with her present program." "He'd just be upset with any talk about change." "He says he wants a change, but he doesn't really mean it." "She can't make a choice." "He has a guardian; so he has no rights."
- Others will see self-determination as a reason to disengage from people, leaving them to deal with the consequences of poor decision making alone because "self-determination means doing it by yourself." This represents a denial of the reality of disability rather than a willingness to search for new ways to support and assist people with significant disabilities.
- The very human process of struggling to balance individual will with responsibility to others, limitation with possibility, and risk with reward will somehow be dehumanized into a technical process that tries to provide neat answers for the basic dilemmas of any person's life. Succeeding at pre-defining "the answers" to these difficulties would mean failing to allow for self-determination.

Most Important Contributions of the Self-Determination Project

Participants imagined that it was June of 2000 and described their idea of the most important contributions the self-determination project made in the course of its three year life. Looking back from its end, people would like to be able to say…

- Many people with disabilities and family members say that the project gave them helpful contacts, useful information, challenging encouragement, and practical help to advocate for themselves and to take increased control of the ways in which they receive assistance. They say that they understand the system better and that they are using their knowledge to make real improvements in their lives. There are still many problems and barriers and

frustrations, but they feel like they have more power because of their connection with the project. A number of new people have defined themselves as advocates not just for themselves, but for other families and for other people with disabilities.

- The project has played a significant role in strengthening self-advocacy organizations. It has helped groups to network on a regional basis and helped self-advocates and members of family advocacy groups to form productive links. As part of its efforts to encourage people to organize, the self-determination project has helped the system to redefine its understanding of confidentiality to reduce barriers to person-to-person and family-to-family contact.
- The links that people have made are beginning to result in more influence in the political process. For example, people and families involved with the project have played an important role in influencing the legislature to fund a priority for the adult services system to continue support to high school graduates.
- Designated agencies and certified providers have learned from the design of the self-determination project and created paid teams that meld the experience of people with developmental disabilities, family members, and professionals to provide a local resource to personal planning and service development. The idea of honoring different kinds of experience and learning rather than just focusing on years of formal education has opened up new job opportunities for people with disabilities and family members.
- Managers with lead responsibility for designated agencies have come to see the project as important to their improving their agencies. They say that the self-determination project has helped keep them honest about identifying and dealing with barriers to people living in ways that make sense to them and the people who care about them. Many of them have made regular attendance at project meetings an important part of their schedule. By implementing their informal slogan, "Don't take no for an answer", the project has pushed them to...

  ...make the most of the increasing flexibility in the system since the July 1998 implementation of waiver amendments that define "flexible supports" as a broad funding category and allow for "one time waivers".

  ...examine situations in which their concern for liability functioned as an excuse for avoiding positive changes.

Project contributions...

- DDS managers and Departmental managers say that the project has helped to clarify the human consequences of restructuring. Participants in the self-determination project have tested the new positive possibilities of restructuring from the first days of its implementation. they have also provided careful and informative feedback about problems in implementing restructuring.
- Staff in other human service agencies report adopting some of the promising practices revealed by the self-determination project. They say that they appreciate the project's efforts to disseminate what it has learned.
- People throughout the state see the project as a great source of reliable links to helpful people and practical information about how to deal effectively with the many issues related to hiring, training, and supervising assistants; setting up your own home; home ownership; maximizing income within the changing benefits system; and creative problem solving.
- The project has stimulated important learning about how to mobilize community members and associations to include and support people with developmental disabilities. While there is still a long way to go and people continue to puzzle over many difficulties, there is solid progress on opening the possibilities of support beyond the limits of family and extended family members. The project can share a better informed understanding of how to deal with the negative effects of what some people call "the human service take-over" of the lives of people with disabilities and the challenges and limitations of involving natural support.
- The project has assisted many people and families to take a long term view of their lives. This has not only given people and families a sense of direction, it has brought the system to deeper consideration of its role in helping people to experience smoother transitions. The systems success at responding to most crises had partly obscured the costs to people and families who had to "crash and burn" before the system responds. As one mother put it, "Why do I have to become incapacitated or die before my son can get the support he needs to move into a place of his own?" People and families involved with the project have used the mechanisms for influencing and monitoring area and state "System of Care Plans" to be sure that issues of better transitions from family homes, from residential support arrangements that people have outgrown, from day services that don't match people's abilities and interests, and from high school graduation remain visible and that funds are allocated to move beyond crisis

response. They have assured that the new management information system clearly accounts for people who will benefit from well planned transitions.

- People and families involved with the project have stimulated a careful – and sometimes painful– reconsideration of case management. This reconsideration included thoughtful consideration of...

  ...family members feeling that the case manager's primary role was to hold them accountable to the system

  ...family members experimentation with using money previously allocated for case management to free up their own time to perform tasks that they had previously relied on case managers to do. As one mother said, "When I had a choice between hiring someone to help with household chores to free my time to deal with my child's problems with SSI and all the other service coordination issues and spending my time calling the case manager to make sure things got done, I took responsibility for case management."

  ...questioning assumptions that were valid when large numbers of people lived in institutions: e.g. in the institutional era it made sense to think that everyone needs a case manager who concentrates and holds knowledge of their individual situation as a safeguard against dehumanization; but now many people –even people who were institutionalized– live with others who share their lives and have greater personal commitment and deeper knowledge of them than case managers can be expected to have for everyone on their case load

  ...dealing with the variety of interesting and sensible proposals for use of case management dollars made by people involved with the project

  ...making the most of the new quality assurance and management information systems to reduce costs of accountability

  ...dealing with the effects of increasing numbers of people who choose to use some or all of their available case management dollars outside existing case management programs

  ...informing and negotiating with people over the costs allocated to case management, the wages paid case managers, and what people actually want from their case manager: e.g. a person who has a fine relationship with his case manager who wants to have the person spend more hours assisting him may ask why the case manager's time costs so much and why the case manager spends a number of hours doing paperwork that seems of little direct relevance to the person

Project contributions...

- The project has substantially increased the number of people who can spot the strings that keep appearing to constrain people with disabilities and their families and take action to cut as many of them as possible. People not only know the mechanisms of the system better, they also understand the ways in which the system controls them in deeper ways that guide better informed action.

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